Response to:

Nobody's Children – Inquiry into the early intervention and care of vulnerable infants in the ACT.

April 2008

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Terms of Reference

To inquire into and report on the early intervention and care of vulnerable children in the ACT, focusing on the unborn child and infants aged 0-2, with particular reference to:

- Children of drug affected parents;
- Antenatal and postnatal care and support services available for vulnerable parents and their children;
- Early identification of a child at risk;
- Specific issues related to indigenous parents and children; and
- Any other relevant matter.

Introduction

SIDS and Kids ACT fully support this inquiry and congratulate the ACT government on their commitment and approach to this important issue.

It is well documented that a significant percentage of families that experience a death due to Sudden Infant Death Syndrome (SIDS) or other Sudden and Unexpected Death in Infancy (SUDI) have chaotic, itinerant lives characterised by social problems such as sub standard housing, unemployment, illicit drug use, multiple partners and domestic violence. Social disadvantage is an important factor when considering the epidemiology of SUDI, however it should not be dismissed as an un-modifiable risk factor. Rather, preventative programs need to address the social circumstances into which infants are born, in addition to promoting parental behavior change. The social conditions of these families make them difficult to reach through traditional public health education strategies. They may require more direct intervention to ensure that messages are understood and implemented. Furthermore, high-risk families in which children do die sudden and unexpectedly need to be provided with accessible and appropriate bereavement support programs to avoid the long-term effects of complicated grief.

Definitions

1. SIDS – Sudden infant death syndrome. The sudden and unexpected death of an infant under one year of age, with onset of the lethal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a complete autopsy and review of the circumstances of death and the clinical history.[1]
2. SUDI – Sudden unexpected death in infancy. Those deaths that fall within the ICD-10 category *Ill-defined and unknown causes of mortality.* Within this category, the two major sub categories are *sudden infant*

[1] Krous, H., Beckwith, J., Byard, R., Rognum, T., Bajanowski, T., Corey, T., Cutz, E., Hanzlick, R., Keens, T. & Mitchell, E. (2004). Sudden infant death syndrome and unclassified infant deaths: A definitional and diagnostic approach. Pediatrics, 114(1), 234–238.

death syndrome (SIDS) and *other sudden deaths, cause unknown.* These deaths comprise the largest group of post-neonatal infant deaths.[2]

3. Stillbirth – A child that exhibits no sign of respiration, heartbeat or other sign of life after birth, and that is of at least 20 weeks gestation or, if it cannot be reliably established whether the period of gestation is more or less than 20 weeks, with a body mass of at least 400 grams at birth.

SIDS and Kids ACT

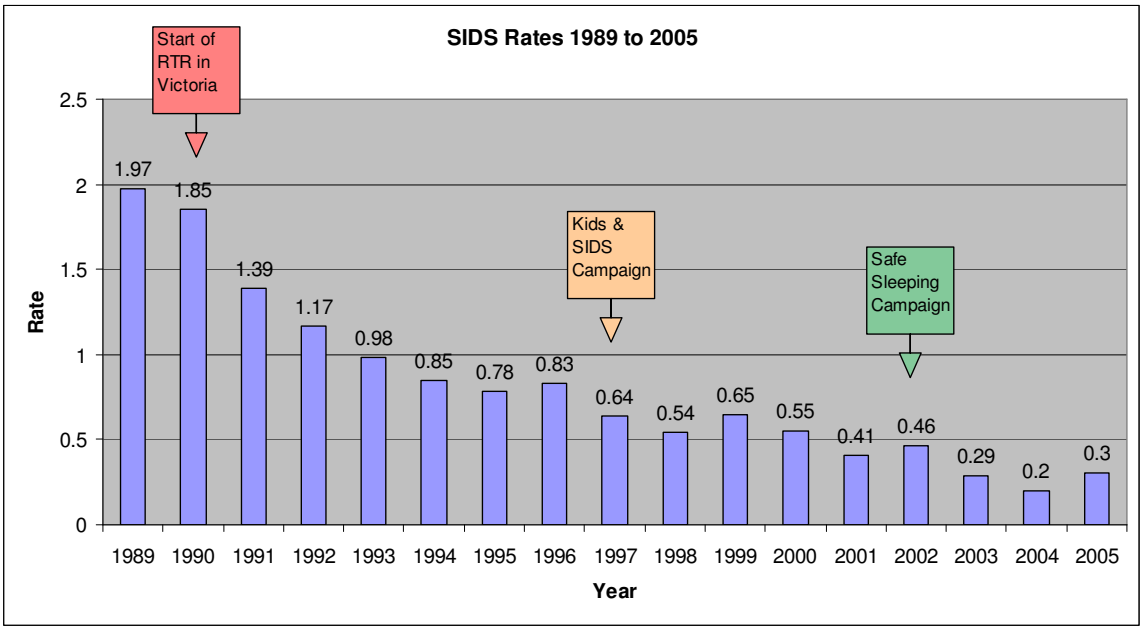
SIDS and Kids ACT is a not for profit charity organisation dedicated to:

1. the elimination of sudden and unexpected death in infancy (SUDI).
2. the provision of bereavement support following the sudden and unexpected death of children under the age of 6 years.

As part of a national movement, we work towards achieving our mission through support and advocacy of research, delivery of safe sleeping education programs and provision of bereavement support programs.

Safe Sleeping Education Program

The national SIDS and Kids Safe Sleeping Education Program has been in place since 1997, since which time there has been a significant reduction in the incidence of Sudden Infant Death Syndrome (SIDS) nationally. In the ACT we receive some government funding through a service funding agreement with ACT Health to support the delivery of our safe sleeping education program.



[2] ACT Child Death Review Team (2006) *Review of ACT Child Deaths 1992-2003.* (Brisco N) Population Health Research Centre. ACT Health. Canberra

Ongoing delivery of this program is essential to ensure that all parents are informed of the risk factors for SIDS and fatal sleep accidents and are able to modify their baby's sleeping environment accordingly. Whilst this program has been a great success, there are still a number of babies who die each year from SUDI, SIDS or fatal sleep accidents in environments where there are modifiable risk factors present. Furthermore, there was a 50% increase in these deaths between 2004 and 2005[3]. Whilst these statistics should be viewed with caution due to disparities in the classification of SIDS and SUDI between States and Territories, it is clear that many of these deaths are potentially preventable.

Recent death reviews undertaken in NSW in 2005[4] and 2006[5] and Queensland in 2005[6] found that 95.8%, 87% and 100% respectively of babies who died suddenly and unexpectedly had one or more modifiable risk factors present in their sleeping environment at the time of death. These risk factors include tummy and side sleeping, head covering with unsafe bedding, exposure to tobacco smoke during pregnancy and or after birth, and co-sleeping in combination with smoking. In addition, these death reviews consistently show that a significant number of SUDI occurred in chaotic, poor households, characterised by significant social problems where multiple independent SIDS risk factors converge. The 2006 NSW death review found that 40% of SUDI were infants identified as vulnerable.[5]

Locally, the Review of ACT Child Deaths 1992-2003[2] found that SUDI accounted for 10% of all infant deaths during the reporting period however, unfortunately, the ACT report does not include any information about modifiable risk factors present in the infants sleeping environment. Since this time local protocol has changed and a medical specialist now attends all child death scenes and considers the sleeping environment, however this information has not been reported publicly since the 1992-2003 review. More recently the Murray-Mackie Review commissioned by the Department of Disability, Housing and Community Services (DHCS) in April 2006 to review the individual cases of five infants/children of which three infants died, found that the infants sleeping environment was a contributing factor to the death. This led to a recommendation related to sleeping practices and environments.

[3] Australian Bureau of Statistics. 3303.3 Causes of Death, Australia - 2005. Canberra: ABS, 2006.

[4] NSW Child Death Review Team (2006) *Annual Report 2005*. (Winter v, Gosley J) NSW Commission for Children and Young People: Sydney

[5] NSW Child Death Review Team (2007) *Annual Report 2006*. (Winter v, Gosley J) NSW Commission for Children and Young People: Sydney

[6] Commission for Children and Young People and Child Guardian (2005). *Annual Report: Deaths of children and young people. Queensland 2004-05*. Brisbane: Commission for Children and Young People and Child Guardian, Queensland Government

This recommendation was as follows:

That consideration be given to a joint project with ACT Health to develop and implement a Territory wide policy to be followed by all relevant staff including midwives and health workers about the provision of information to new and expectant parents about safe sleeping practices. Further, that ACT health develop a training package that includes culturally appropriate materials and communication strategies that convey consistent messages about safe sleeping, particularly to high risk and vulnerable families.

In response to this recommendation and in recognition that SIDS and Kids ACT are funded by ACT Health to provide safe sleeping education to professionals and the community, consultation was held in relation to further educational and training opportunities between SIDS and Kids ACT and the ACT government. Joint training days were held with Community Health staff and Care and Protection workers to increase the knowledge and understanding of safe sleeping messages.

A project was also funded jointly by ACT Health and DHCS for SIDS and Kids ACT to develop a low literacy safe sleeping brochure which will effectively deliver the key messages to those groups at highest risk. This project will be complete by June with the brochure ready for distribution throughout the Territory.

However, this resource alone will not affect behaviour change in high-risk groups. There is a need to ensure that the messages are constantly and consistently reinforced by all professionals in contact with high-risk families. This will require a territory wide multi agency policy development involving all service providers who have contact with high-risk groups within our community. It is important that this is not seen as a role for Care and Protection alone as early intervention through midwifery and maternal and child health services will ideally help affect behaviour change prior to the involvement of care and protection services.

SIDS and Kids ACT are making concerted efforts to ensure that our current education program is delivered to all agencies who have contact with high risk families during pregnancy and the first two years of life. By presenting the evidence behind the recommendations, professionals working within these agencies are better equipped to check infant sleeping environments during home visits and to discuss this with families.

Whilst many professionals are keen to attend education sessions, there are many who do not, yet there is reliable anecdotal evidence in the ACT that some health professionals knowingly and deliberately disregard the safe sleeping recommendations by placing babies to sleep on their side or tummy. As midwives are the most influential role models for parents, this can have a profound impact on mothers who are more likely to practice what they see.

If this education program was supported by territory wide policy it would support the implementation of mandatory safe sleeping education for all professional groups. NSW and QLD Health already have such evidenced based policy in place. The existence of policy adds credence to the importance of infant safe sleeping practices and would influence health professionals to comply with rather than disregard the information.

In order to fully realise our aim of ensuring that everyone within our community have the capacity to sleep their babies safely, there is a need to review the current model of delivery of the program and adapt it to better meet the needs of vulnerable groups. This would, however, be difficult to achieve within existing resources.

Bereavement Support Services

Due to the fact that infant mortality rates remain higher in the vulnerable groups within our community, it is necessary to ensure that effective bereavement support services are available. Unfortunately, until the disparity in the infant mortality rate is addressed and reduced, this will continue to be the case. The death of a child is one of the most traumatic events to impact on a family and when that family is already living within a chaotic environment due to social disadvantage and its related problems, the grief response can be increasingly complicated.

It is vitally important that these already marginalised groups are not further isolated through lack of access to appropriate support services. SIDS and Kids ACT provide a wide variety of bereavement support options to families. However those with problems associated with social disadvantage, including co-existent drug and alcohol use and/or mental health problems, need specialist care. To this end it is essential that interagency partnerships are brokered to ensure that effective and accessible support is available.

Stillbirth

There are approximately 1400 infants stillborn in Australia each year. The vast majority of the clients accessing the SIDS and Kids ACT bereavement support service have experienced stillbirth. The Stillbirth Foundation Inc. is currently funding a comprehensive review of the risk factors for stillbirth, which is being undertaken by the Perinatal and Epidemiology Unit of Mater Health Services, Queensland. Whilst we await the results of this review to provide conclusive evidence of causal links between risk factors and stillbirth, there is clear evidence linking low socio economic status with increased risk. Several studies have identified social disadvantage, aboriginality, smoking, young maternal age and obesity as risk factors for stillbirth.

Hence the same groups who are at increased risk for SUDI are also at increased risk of stillbirth. This means that it is vitally important that all pregnant women are able to access quality antenatal care regardless of their social circumstances,

ethnicity or age. This antenatal care needs to provide both support and education to address risk factors and hence improve outcomes. Whilst social disadvantage and the concurrent social problems associated with it may not be easily addressed, providing universal access to appropriate support is an essential first step.

Recommendations

1. The ACT government should consider investigating the possibility of initiating a process aimed at achieving a national standard death scene investigation protocol and standardised classification and reporting of SUDI deaths.
2. The ACT government should consider re-establishing an active ACT Infant/Child Death Review Committee. This could be attached to the existing ACT Perinatal Mortality Committee.
3. The Committee described in recommendation 2 should be charged with undertaking another Child Death Review of all deaths since 2003 which includes a description of the environment in which the child/infant was discovered and identification of any modifiable risk factors in the sleeping environment. They should then investigate all deaths on an ongoing basis.
4. The ACT government should progress consideration of recommendation 16.1 from the Murray-Mackie Report in relation to the development of a territory wide policy. This would include the development of a territory wide policy for practitioners and a comprehensive education program – ideally safe sleeping education should form part of the annual mandatory organisational education program for all staff.
5. The ACT government should support the review of the model of delivery of the safe sleeping education program to ensure it effectively targets high-risk groups.
6. The ACT government should support government and non-government interagency partnerships to ensure that appropriate and effective bereavement support services are available to high-risk groups.
7. The ACT government should support the implementation of antenatal education programs aimed at specific high-risk groups. Due to the itinerant nature of some of these individuals, innovative approaches to settings and models of delivery should be considered.

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